Mississippi Council on Developmental Disabilities Sponsored Planning Alternative Tomorrows with Hope (PATH)

Agency Representatives/Individuals with Disabilities/Family Members Joint Needs Description and Strategic Planning Meeting

Agenda: Path to a Unified Meeting of Needs

A dream
Some long term goals
Some shorter term smaller goals
First steps towards reaching these goals
Ways to build strengths needed to reach goals
People who need to enroll in the commitment towards the goals

First steps: Enunciate the dream, specify goals towards that identified dream, and clear accounting of current realities.

Next steps: People needed and strengths needed and steps to take to reach the goals and dreams.

Step 3	Step 4	Step 5	Step 8	Step 7	Step 6	Step 2	Step 1
Grounding in the Now	Identifying People to Enroll on the Journey	Ways to Build Strengths	First Steps	Next Months Work	Action Steps for the Year	Sensing the Goal	Touching the Dream
Present reality, what currently exists. Issues unsolved. See the difference between the now (on left) and possible future (on right. Purpose of PATH is to get from now to the goal.	Indicate desire to move forward; commit to the process. Add people to the group that weren't here today (specific names and categories of people); change can not be accomplished alone.	Strengths the individuals and group will need to move along the PATH towards the goals (knowledge, skills, helpful relationships, individual expertise). What is needed in order to be strong enough to keep moving forward and reach goals.	Action that can and should be taken immediately.	Repeat of step 6, but thinking closer to today: who will do what, when, and where?	Main actions required to arrive at goals. Think positively; assume things are going well.	What you create to approach the dream. The results after effective work. The resulting success and needed change. Actual objectives for this year or next.	The vision. The seeds for the future; the driving force; the hope. What motivates; gives direction. Needs you wish were met "jointly" and didn't have to fight for all the time.

May 17 - 18, 2005 PATH Report

Mississippi will become the leader in best practice for full inclusion and services for everyone.

Step 1

The Vision

The dream.

The seeds for the future; the driving force; the hope.

What motivates; gives direction.

Needs you wish were met "jointly" and didn't have to fight for all the time.

Single Point of Contact with Comprehensive Resource Information Leading to "Single Point of Entry"

- User friendly (toll free number & web sites of resources and information) including information about all available resources; SB 2931 passed and needs to be implemented
- Interagency collaboration for overlapping, linking of services effective planning to stretch the resources, efficient use of public resources, federal approval for shared or blended funding
- Legislative action to prioritize funding shifted dollars, smart spending, with priority on home and community based waivers
- Life-long, independent case management ("single point of entry") case management for even those waiting for services (explanation of resources, connection to other alternatives)
- Education, transportation, housing, employment, recreation and welfare systems serving all groups disability, elderly, low income.

Medical Care

- Uninterrupted coverage, including equipment and medication equipment which includes assistive technology for communication, mobility, education, housing, employment and recreation
- **Medical workers trained in sensitivity** knowing about and connecting to the potential supports; building on the best possible vision of future for a child
- Broader model of "medical home" case management for all of life areas

Services

- Consumer and family directed & monitored; "money follows the person" piloted service planning in partnership/collaboration between providers and with parents monitoring everyone (service providers, consumers) for accountability, stopping any abuse of the system
- Well trained administrators and providers AND direct support professionals (DSPs) DSPs with knowledge specific to individual with disability, an attitude and philosophy that values and respects, relational service delivery that recognizes humanness (i.e. bad days are OK), use of respectful age appropriate resources and materials a career ladder and better pay and benefits for DSPs
- Support services based on specific individual needs use of person centered planning
- An organized system with a pool of candidates for backup AND emergency options AND consideration of a single waiver for quality services for all
- Emphasis on care for aging

Step 1	Inclusive/Model Schools
The Vision (cont.)	 Philosophy/practice of educating ALL to their highest potential (0 – adulthood, including higher education) Administrators, teachers, and assistants well trained and qualified for

- Administrators, teachers, and assistants well trained and qualified for inclusion, transition, and partnering with families
- **Smooth transition** from medical services to early childhood to school to adult services
- Adequately funded of related services speech/language services, including augmented communication, and Occupational and Physical Therapy

Accessible Communities (Housing, Transportation, Employment, and Recreation)

- Safe communities with trained law enforcement
- **Physical structures accessible** businesses and public settings
- Inclusive (affordable and accessible) community programs for choice and quality of life housing, transportation, employment, and recreation (including church options)
- **Real options available** not just existing resources, run by State agencies
- "Customized" employment options
- Transportation when, to where needed and wanted freedom, spontaneous access
- **Choice of living arrangement** individuals choosing where, and with whom to live and participate in recreation with
- Varied levels of support available per each option
- Assistive Technology services across all areas of life education, living arrangements, work settings, and recreational settings (i.e. alternative computer access, adaptive recreational equipment)
- **Positive media portrayal of disability** including promotion of prevention of disability (i.e. warnings about fetal alcohol syndrome and drunk driving)
- Changed community attitudes individuals with disabilities seen in a positive light without prejudice or stereotyping acknowledgment of the power of the individual ALL are respected and valued (in representation, spending, accessibility issues, voting)

Supports for mentoring, advisory roles, and leadership development

- Family to family mentoring and support
- Peer to peer mentoring and support
- Sibling to sibling mentoring and support
- Avenues of expression to give voice to needs, desires heard and responded to by federal government, state agencies and service providers able to talk about real supports for families and individuals with disabilities, including parents with developmental disabilities who have typical children.
- More people with disability in leadership positions

The Goals

Strategies to meet needs and reach the vision.

→ Concentrate on collaborative strategic planning to meet needs

- Any task force (housing, employment, transportation support) should be inclusive of individuals with disabilities, family members, and agency representatives
- A task force is needed for addressing life planning for children of aging parents
- National trends should be identified and considered, in order to be proactive rather than reactive
- → Organize a needs "description" by ALL individuals with disabilities and their family members so the voice is "louder and clearer"
 - Find out what ALL people being served really want and need
 - Any future PATH process would continue to include more and more partners
 - Develop a needs survey to verify and prioritize the needs described by the PATH groups and people's preferred ways to have these needs met
- → **Disseminate information** about ALL agency policy, procedures, regulations and available services in a data base format as well as other user friendly methods:
 - Phone contact
 - Internet website
 - Print materials
 - Media (radio, television)
 - Getting Information to schools teachers and counselors and churches to share with families and individuals with disabilities on how to access all possible services (including Social Security program)
- → Support "inclusive" programming across ages (childcare through aging) and across support needs (i.e. education, transportation, housing, employment, and recreation)
 - Establishing new programs in response to updated needs description
 - Improving existing programs raising the incentive for inclusion, lowering the liability issues
 - Continuing programs in response to updated needs description
 - Monitoring programs for quality & outcomes (measured per individual and program descriptors)
- → Educate, rather than "train", and organize support groups, for:
 - Families and individuals with disabilities
 - Providers (including direct support providers using the College of Direct Support Professionals curriculum which covers "best practices" for community supports)
 - General Education teachers as well
 - Administrators
 - Legislators
 - The "public"
 - "General public" community service providers
 - Modeling acknowledgement of the strengths and contributions possible by people with disabilities (i.e. influencing the employment world)

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The Goals (cont.)

- Developing and implementing education/training programs that are disability specific and sensitive to the issues of people with disabilities understanding "people first" philosophy and practices (i.e. education programs for transportation providers)
- → Increase funding for community services pursuing all the grants that are available related to disabilities, aging, low income and community development
 - Adequate funding for administrative, organizational, staffing, and direct service needs – for education, transportation, housing, employment and recreation supports
 - Piloting of "money following the person"
 - Increased funding for assistive technology services and equipment
 - Adequate funding for medication
 - Review and evaluation of the use of the available dollars, based on outcomes data and measures of quality for education, transportation, housing, employment and recreation supports

→ Use existing systems change strategies

- Form a task force to review state plans, regulations, and services enforcing the response to the Olmstead Decision in the Mississippi Access to Care (MAC) Plan
- Examine ALL possible waiver options perhaps developing one waiver for quality services customized on individual need
- Increase interagency collaboration and joint funding
- Learn from other states, particularly long term care preparedness strategies
- (1) There is a national tool on the web from CMS developed by consultants for reviewing Home and Community Based Waiver Services for quality that can be accessed and disseminated.
- (2) There are other states successfully addressing shortfalls reallocating dollars to save money while supporting community services.
- (3) A pattern modeled from the current DMH/Medicaid Real Choice Systems Change transportation initiative, Jan Larsen Coordinator, could be applied as a strategy for blended funding for supports and services for an individual in any life area, not just transportation.

→ Practice Advocacy

- Influence appointments so that people in positions of authority include people with disabilities or people who can advocate for them
- Support positive media portrayal of people with disabilities use media to illustrate success, dollars saved with successful employment and community based services
- Ensure that "hidden" disabilities are represented and protected (i.e. those that are underserved)

Concentrate this PATH group's effort - prioritizing and selecting four goals and activities that will address as many needs as possible – successfully – this year.

The Areas of Need

- Locating and accessing resources; information gathering
 - O People who have never accessed resources (not in the system) until there is a crisis.
 - o People without Medicaid
- Medical supports (birth; health; dental)

Present reality; what currently exists; issues

unsolved.

See the difference between the now (Step 3) and the possible future (Steps 1 and 2).

The purpose of PATH is to get from now to the vision and goals.

- Early Intervention services (evaluation; planning; implementation of services; transition)
 - o Accessing the EPSDT services
- Educational systems (evaluation; planning; implementation of services; transition)
 - Access to FAPE (free appropriate public education) including access to higher education
 - A clear understanding of a what a good IEP looks like
- In-home and in-community (especially rural) supports; including childcare
- Housing options
 - Stable housing so that people can be employed
 - o Prioritized Section 8 housing for people with disabilities
 - One of the top three needs, say 300+ individuals with developmental disabilities
- Recreational/social options
- Employment options
 - o More employers knowledgeable about disability hiring
 - One of the top three needs, say 300+ individuals with developmental disabilities
- Transition (agency to agency; lifespan issues)
- Parents with disabilities with typical children
- Service coordination; individualized and independent case management
 - o "Under service" because of lack of flexibility to rearrange what the person really needs
- Person directed (controlled) services
 - o Results from the satisfaction surveys really put into the action; the results of the information used to improve services
- Transportation supports for medical appointments, work, fun (door to door vs. fixed route)
 - One of the top three needs, say 300+ individuals with developmental disabilities

The Areas of Need (cont.)

- Community safety
- Aging issues caregivers aging creates crisis (Where to go, How to get there, When to plan, Awareness of waiting lists)
- Services and equipment for assistive technology evaluation, communication, and mobility; meeting the needs for environmental controls in living arrangements, access to education, employment and recreation options
- Family supports respite, behavioral supports, legal supports and future planning, connection to other advocates, education about resources
- Provider supports and education/training
 - o Motivated compassionate caring providers whose own needs are met
 - Qualified professional staff education/training provided from upper level down to direct support
 - O Disability specific and general disability understanding; knowledge on how to use assistive technology equipment
- Systems change
 - o More flexibility (real choice and options for services)
 - o Efficient and effective use of funding

What's important to you; what are your priority needs?

How satisfied are you now; which needs are being met and which needs are not being met?

How would you like your needs met?

People to Enroll on the Journey May 17 - 18, 2005 PATH group indicating desire to move forward; commit to the process. Adding people to the group that weren't there (specific mames and categories of people); change can not be accomplished alone. People to disseminate PATH report to and invite to next PATH meeting Secretary of State – Eric Clark Medicaid Office Rep – Mike Gallarno and/or MAC Plan represenative WIN Job Center – Bob McDonald Department of Education – State Independent Living Council / CAP – Pressley Posey Catholic Charities – Linda Raff Choctaw Indian Nation – Mary Meruvia National spokesperson – Greg Smith LIFE – Christy Dunaway MS Housing Authority – 4-H – Mississippi State – Dr. Susan Holder HUD – USDA – Protection and Advocacy – Becky Floyd Department of Health, Part C Coordinator – Danita Munday MS Arts Commission – State Rehab Council – Bruns Meyers AARP – United Way – MS Center for Justice – TEAAM – Pam Dollar Law Enforcement – Medical Representative (physician, therapist, insurance representative) MS Dept of Public Health – Gwen Winters Agency Directors	Step 4	See May 17 – 18, 2005 PATH participant list			
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CDD members – All who would want to participate, particularly people on the state		CDD members – All who would want to participate, particularly people on the state			
plan committee and chairpersons of relevant "area of emphasis" committees		plan committee and chairpersons of relevant "area of emphasis" committees			
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8

The PATH Group Needs

Ways to build strengths to reach outcomes

Strengths the group will need to move along the PATH towards the goals (knowledge, skills, helpful relationships, individual expertise).

- Collaboration on whatever the issue for instance, work together for joint funding (i.e. in-depth analysis of all five Medicaid waivers including funding streams, expenditures, allocated dollars, services provided)
- Information gathering and sharing to locate additional funding sources and support of each other in current project efforts and in future efforts
 - e.g. support of current DHS aging projects
- Narrow the PATH focus
 - Create obtainable goals
 - Solve a limited number prioritized issues first
 - Develop action plan that can really be implemented
 - Identify specific people to do the leg work and let others know who that is and deadlines
 - Instill hope so commitment is sustained
 - Show results publicize results to promote buy-in
 - *Get feedback from policy makers*
- Modify the list of participants to include what each person actually does as part of their agency or organization for immediate use in "who to contact about what"
- Sound like a bigger voice continued and more involvement from individual with disabilities and family members capture the bigger voice through an updated needs survey across ages and disabilities

The	Collaboration Efforts
Current Situation -	• Funding sought for DHS aging grants – join the effort
What's	Shared needs assessment information already conducted or being conducted –
Being Done	Epilepsy Foundation in North MS is 1 of 3 out of 55 national models
G	The DMH report from the Office of Constituency phone calls for information
Strategies to build on	summarizes types of needs being requested and a growing system of MS resource listings by geographic area
	Sharing of Resource Information Possibilities
	The PATH Report and continued efforts of needs description will on the
	Council on Developmental Disabilities website by July 1, 2005
	 DMH will soon make state plan and service description available on web site Look at the Memphis system for a good example of 1-800#, data base, etc.
	Case Management Ideas
	 There are private insurance company models of "independent case management to be studied.
	Housing Supports
	USM IDS HOYO (Home of Your Own) program
	• USM IDS Shelter for All program (for those at-risk for homelessness)
	CDD funded Creative Community Living Options - CCLO project
	 Ongoing Olmstead settlement in MS – making available names of people wanting less restrictive living arrangements & resources to support them in their move
	Transportation Strategies
	• United We Ride, a US Dept of Medicaid initiative, seeking to spend
	transportation money more effectively – across agency transportation
	 A Real Choice Systems Change demonstration grant – collaboration between MS Medicaid and Dept of Mental Health – piloting in Region 15 Community Health Center – Determining where the transportation money is being spent in the area, who uses it, who needs it, sharing resources. This will be an example of a single point of entry with multiple funding streams depending on why and where you are being transported.
	Recreation Options
	• Inclusion through Recreation Conference – June 9 & 10, Jackson Holiday Inn
	Rick Green's leisure/recreation pyramid concept
	• Fitness for All Project (TLC)
	o Accessible Tree house
	Fragrance GardenTechnology Learning Center
	- Technology Learning Collect

- o Accessible golf cart
- Accessible kayaks
- Beach wheelchairs
- Sport chairs
- o Tennis lessons
- Hand cycles
- Adaptive fishing equipment(off and on shore)
- o Dock lift
- Accessible park being developed off Ellis Avenue by Coalition
- Accessible park for low vision in Biloxi
- Camps Arthritis camp, Low vision camp, epilepsy, autism
- Camp Jabber Jaw for children with communication devices
- Healthy Futures camp and retreats
 - New funding soon

Assistive Technology Resources

o MDRS Project START funds are still available

Education/Training Supports

- CDD and ARC of MS Direct Support Professional Opportunity curriculum
- Vicki Killingsworth is available as a consultant to provide sensitivity training particularly with employers
- UMC addressing medical personnel rape kits, etc.
- IDS Project Haven training of law enforcement
- Council on Epilepsy provides disability training to transportation providers

Potential Action Steps	Become a unified voice at National Summit (September in Washington D.C.) – consider similar State Summit in the future
Thoughts	 Decide which issues (needs/strategies) to begin with (prioritize)
from the first day of May 17 - 18, 2005 PATH	 Clarify and target specific issues to address and actions to implement Be one voice / work smart / focus on sharing resources; doing it differently Decide what is doable for success
group	
meeting	 Market – build awareness of: Systems Resources Waiting lists Opportunities Benefit/futures planning
	 Market – build awareness to: Providers Families Government officials Law enforcement City government
	 Consider Blanket waiver – using collaborative blended funding for an individual
	Plan for aging issues NOW
	Become involved in Consolidated State Plan for Housing
	 Use Secretary of State's website for review of public comment Conduit for comment when you are not heard during a state planning process
	 Support each other efforts (i.e. Coalition considering grant to train people with developmental disabilities and aging individuals to become Personal Care Assistants – Coalition can also collaborate with CDD and ARC of MS Direct Support Professional Opportunity project)

S4 (Tree L All	
Step 6	Efforts by All	
Action Plan to Accomplish by May of '06 Main actions required to arrive at goals.	 → The 4 PATH Task Force groups should maintain interagency representation as well as representation from families and individuals with disabilities. ■ Creating a picture together of what the 4 focus efforts could and should look like. → Each Task Force should create a concrete plan for achieving their goal and share it with the entire PATH group for support. ■ PATH members and CDD members could use opportunities to share information with the governor and legislators they know. → The PATH group should advocate on behalf of Task Force member who seek to 	
Think positively; assume things are going well.	pilot initiatives to demonstrate new national trends in the 4 focus areas. ■ A potential CDD initiative could be to pull together any existing education/training efforts of transportation providers (including disability specific skills, sensitivity issues, and situational judgment) and add the "voice" from the My Voice – My Choice group. → PATH meetings should be used for sharing information on accomplishments related to meeting the described needs: ■ Product soon to be published by CDD Project SUCCESS on how to support individuals with developmental disabilities be successful in higher education settings.	
Step 7	Marketing Efforts	
Action Plan to Accomplish by December of '05	Someone knowledgeable of the PATH efforts should sit on the Governor's Commission on Disabilities, if possible. Max Wells will inform Ed Butler if this is possible and how to make this happen. → This person should be able to present the data (on need and possible models to pilot) gathered by each PATH Task Force and the concrete plan suggested by each Task Force to accomplish their goals.	
Repeat of step 6, but thinking closer to today: who will do what, when, and where?	Ed Butler will invite Greg Smith to the next PATH meeting – planning for media coverage of the PATH efforts. Charity Drummond will be organizing an effort to support the PATH activities among the 300+ individuals with developmental disabilities reached by the ARC of MS – My Voice, My Choice Project.	
Step 8 Action	Formation of 4 Task Force Groups Addressing Prioritized PATH Goals	
Plan to Accomplish by August of '05	Immediate Steps for Each Task Force: → A leader needs to volunteer from each Task Force and contact Linda McDowell. → The leader needs to then contact Task Force members listed to date and decide together on new members to enlist (see Step 4 for potential members). Someone on each Task Force could volunteer to help enlist. Ed Butler and Grenaye Sullivan will	

Action that can and should be taken immediately. be disseminating the PATH Report and will be soliciting CDD members (particularly, relevant "area of emphasis" chairpersons) to join Task Force groups.

- → The leader needs to encourage Task Force members to volunteer for tasks listed under Step 6 & 7 and begin Steps listed below.
- → Additional activities relevant for addressing each Task Force focus can be found under Step 2.
- → Each Task Force leader should come prepared to report on their specific plan and/or progress at the next PATH meeting.

1. Affordable Housing Options

Members to date: Carolyn Taylor, Brenda Havens, Charlotte Myers, Lisa Besnoy, Shirley Miller, Jackie Breland

Tasks:

- The CCLO project could be a pilot for Money Following the Person have this discussion with members of Task Force #2. Conversations should be held with Ashley Lacoste and Ed LeGrand on how to meet Medicaid and DMH training standards in this pilot effort – consider the Direct Support Professional Opportunity.
- Continue to research potential housing options to pilot and the appropriate partners to collaborate with.
- A method for documenting the money savings with any of the options piloted should be implemented as well.

2. Piloting of Money Following the Person (Person Directed Services) & a single flexible waiver system

Members to date: Ellen Saunders, Betty Busbea Tasks:

- The wide variety of "person directed service" models should be researched and described of (i.e. micro-boards, fiscal intermediaries) split the research effort with Task Force #1.
- Determine what efforts the Coalition is making on informing and education legislators on the cost benefits and quality of service benefits of Money Following the Person, join and/or expand.
- Research the possible models of and benefits of a single flexible waiver system – or blended funding for an individual from several waiver sources (shared interagency funding to meet an individual's diverse needs).

3. Meeting Identified Needs with Comprehensive Listing of Resources and Development of Independent System of Life-long Case Management ("Single Point of Contact")

Members to date: Shannon Rushton, Max Wells, Beth Scarborough, Annette Reinhart, Judy Duncan Tasks:

- Decide on most effective and efficient method for summarizing needs obtaining an even "louder and clearer" voice (1) see current survey results from other disability organizations DMH, Epilepsy, (2) study examples of surveys to use CDD groups, and (3) consider ways to use the PATH summary of need as a part of this effort.
- Support/modify efforts in the state to have comprehensive listing of resources

(new Governor's Commission, DMH computer system).

• Study other models of life-long case management from other states (see examples mentioned under Step 5.)

4. Accessible Transportation for Recreation and Employment

Members to date: Jan Larson, Anita Kegley, Charity Drummond Tasks:

- Study suggested strategies current efforts underway listed under Step 5.
- Consider taking a lead in developing an organized effort for training of transportation providers.
- Research and support specific efforts in the state to provide a variety of community options for recreation and employment – adding solutions for flexible, accessible transportation.

Next PATH meeting - ALL Task Force members to attend

August 23, 2005
Cabot Lodge on State Street in Jackson
9:00 – 3:00, Lunch provided
Please let Grenaye Sullivan know of your plans to attend